

**Demand
early diagnosis,
save lives**

**Sarcoma UK's
pledge to improve
early diagnosis**



SarcomaUK

The bone & soft tissue
cancer charity

#SarcomaWontWait

About Sarcoma UK

Sarcoma UK is a national charity that funds vital research, offers support for anyone affected by sarcoma cancer and campaigns for better treatments. It is the only cancer charity in the UK focusing on all types of sarcoma.

Our policy team looks for evidence to develop policy which will influence key decision makers in the Government, NHS, and research communities. We want to make sure everyone affected by sarcoma has access to the best possible treatment and care.

Working across the UK to develop and drive policy solutions, we aim to bring about change by improving outcomes and services for patients with sarcoma.

What is sarcoma?

Sarcomas are uncommon cancers that can affect any part of the body, on the inside or outside, including the muscle, bone, tendons, blood vessels and fatty tissues.

About 15 people are diagnosed with sarcoma every day in the UK. That's about 5,300 people a year.

There are around 100 different sub-types of sarcoma.

Sarcoma diagnoses make up about 1.4% of all cancer diagnoses in the UK.



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Executive Summary

This report outlines Sarcoma UK's pledge to take action to improve early diagnosis of sarcoma in the UK.

The later a sarcoma is diagnosed, the worse the outcome for the patient. Despite time being of the essence, on average sarcomas are diagnosed when they are about the same size as a can of beans.¹

Sarcoma UK recognises early diagnosis as one of the key drivers for improving survival, and through discussions with supporters and clinicians, academic research and through the results of the National Sarcoma Survey 2020, we have so far found three key challenges to diagnosis: public awareness, healthcare professional awareness, and the diagnostic pathway.

“Sarcoma UK recognises early diagnosis as one of the key drivers for improving survival.”

It has been clear from our supporters that, even among themselves prior to their diagnosis, awareness was extremely low. Therefore, the report details how this lack of awareness made sarcoma feel even lonelier and caused patient delay in contacting a healthcare professional.

This lack of awareness and knowledge of how to spot signs and symptoms of sarcoma was also demonstrated in healthcare professionals, so the report also highlights the need to improve their knowledge of sarcoma and awareness of the correct referral path for sarcoma.

Lastly, the report looks at these referral paths and how we must look to ensure that the diagnostic pathway is effective and efficient, demonstrating how patients are currently being referred multiple times, how their scans are not being assessed accurately and how they are not receiving the appropriate care from a specialist centre.

Altogether, this report demonstrates the need for change and serves as our commitment to continue to work towards forming a set of detailed policy recommendations which can, ultimately, improve diagnosis for sarcoma patients.

30%

of sarcoma patients waited more than six months, after first consulting a healthcare professional, to receive an accurate diagnosis.



1 in 6

patients (17%) waited more than a year before receiving an accurate diagnosis.



¹ Grimer, R. J. Size Matters for Sarcomas! Ann. R. Coll. Surg. Engl. 88, 519-524 (2006).

An introduction to early diagnosis



Why is early diagnosis important?

Being diagnosed with sarcoma can often be an isolating and lonely experience, this is only further amplified for patients who have to wait agonisingly long times for their diagnosis.

This can result in poorer patient outcomes and cause great emotional strain.

Simply, late diagnosis costs lives.

Unfortunately, delays in diagnosis for both bone and soft tissue sarcoma are common.

Many of our patient community also tell us that they have received an incorrect diagnosis, which often leads to incorrect treatment and further delays. Although the Government has introduced programmes to increase the speed of diagnosis for suspected cancers, this has had **little-to-no effect on sarcomas.**²



What Sarcoma UK aims to do

Sarcoma UK is conducting in-depth research with our supporter and clinician community to find out more about the current problems with diagnosis.

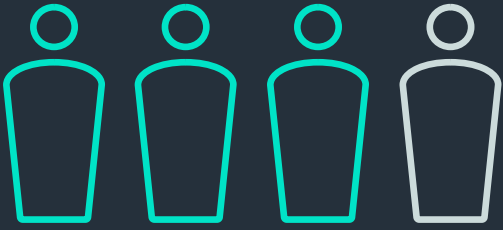
This research will allow us to develop a set of detailed recommendations which will clearly define the necessary steps which we want policy makers to take to improve early diagnosis of sarcoma.

So far, we have identified three key areas which we will look to improve through our recommendations:

1. Public awareness of sarcoma
2. Awareness throughout the healthcare profession
3. Effective and efficient scans and referrals.

This report outlines why it is so important to make improvement in these areas and is our pledge to improve diagnosis for sarcoma patients across the UK.

² George, A. & Grimer, R. Early symptoms of bone and soft tissue sarcomas: could they be diagnosed earlier? Ann. R. Coll. Surg. Engl. 94, 261-266 (2012).



**Our YouGov Poll showed us that
3 in 4 adults in the UK do not know
what sarcoma is.³**



**And of those who said they had
heard of sarcoma, nearly a third
(29%) had no idea of what the
symptoms of sarcoma are.**

³ The survey for Sarcoma UK was carried out online by YouGov Plc between 1-2 April 2020. Sample: 2,007 adults. The figures have been weighted and are representative of all GB adults (aged 18+)

1. Public Awareness

We will be the driving force to improve public awareness of sarcoma's signs and symptoms, working alongside the Government and other public bodies.

The signs and symptoms of sarcoma are varied and the public either do not recognise or are not aware of the symptoms of sarcoma. This means that they are unlikely to see a medical professional soon after symptoms start, particularly if these symptoms are not causing them any immediate pain or discomfort.

Of the people asked in our National Sarcoma Survey, 79% of sarcoma patients said they hadn't heard of sarcoma before their diagnosis.⁴

It also illustrated that one in seven patients wait more than six months from the time they first thought something might be wrong until they first saw a GP, nurse or went to A&E. This is particularly true of 16-to-24-year olds, 25% of whom waited more than a year after they first noticed symptoms before visiting a healthcare professional.

Ultimately, the later you're diagnosed, the lower the chance of successful treatment.

Symptoms of sarcoma

Bone sarcoma:

- worsening or deep persisting pain in any bone
- unexplained difficulty using an arm or a leg
- bone pain that is worse at night
- a lump/swelling
- an unexplained bone fracture

Soft tissue sarcoma:

- a lump larger than 5cm that is painful or painless
- a lump that is increasing in size
- a new lump in the place where a previous lump was removed



"I did not connect my symptoms to cancer at all. If I had any idea that I might have cancer on my thigh, I wouldn't have brushed my symptoms under the carpet. I want everyone to be aware of the signs of potential sarcomas so they can rule it out as early as possible."

Ben Willett, Sarcoma UK Supporter

2. Healthcare Professional Awareness

We will push to improve knowledge and awareness around the signs and symptoms of sarcoma among primary care staff, such as GPs, community nurses, physiotherapists, pharmacists and emergency department workers.

Primary care services provide the first point of contact for those with suspected cancer, and are the 'front door' into the NHS.

For patients with suspected sarcoma to reach the right services as quickly as possible, it is essential that primary healthcare professionals are aware of the signs and symptoms, as well as the correct referral path.

83% of sarcoma patients in our survey saw a GP at their first appointment with a healthcare professional after they noticed symptoms of sarcoma. Despite this, during a working lifetime a GP may see many hundreds of benign tumours, but can only expect to see one or two patients with bone or soft tissue sarcomas.⁵ Other primary care professionals may see even fewer.

Given its rarity, it can be difficult to recognise the symptoms described by the patients as being those of a suspected sarcoma. This means that possible sarcoma patients are either sent away, or put on unnecessary treatment for another condition.

As a result, a third of sarcoma patients (35%) had to see a healthcare professional more than three times before they were referred for further tests.

Problems do not stop here. If the healthcare professional does not suspect these symptoms could be a cancer, more delays can occur, leaving the sarcoma untreated. In England, patients with suspected cancer should always be referred to see a specialist within two weeks, and have cancer either confirmed or ruled out within 28 days.

By empowering healthcare professionals with the knowledge of sarcoma we will give patients the best chance to be diagnosed early and the best chance of successful treatment.

39%

At the first appointment with a healthcare professional, 39% of people who went on to be diagnosed with sarcoma were either started on treatment for something else or were told their symptoms weren't serious.



35%

of patients had to see a healthcare professional more than three times before they were referred for further tests.



⁴ Sarcoma UK National Patient Survey (2020). Unless specified statistics are based on our survey of adults 16+.

⁵ NICE. Improving outcomes for people with sarcoma. (2006). Available at: www.nice.org.uk/guidance/csg9. (Accessed: 9th August 2019).

Charlotte's story

Charlotte Beckerleg tragically lost her father to sarcoma in 2019, aged 50.



“By the time the tumour was finally removed it weighed 2.5 pounds – heavier than a bag of sugar.”

When my Dad found a tiny lump on his thigh there was no thought that this could be sarcoma. His GP initially wrote it off as a cyst, and even when it was the size of a plum considered it as non-urgent for a scan. It was only by the time he could not walk that he finally received the scan which led to his diagnosis; by the time the tumour was finally removed it weighed 2.5 pounds – heavier than a bag of sugar.

Sadly, my Dad is not the only one who has suffered due to the lack of knowledge of sarcoma and I am passionate that this has to change. Since my local GP surgery found out about the outcome of my Dad's case, they used this as an opportunity to find out more about sarcoma and to inform their practice; they have now successfully identified three further sarcoma patients. This proves how essential it is that primary care professionals know about sarcoma and its signs and symptoms and I, for one, will continue to shout my Dad's story far and wide if it can educate others and ultimately save lives.

3. Scans and Referrals

- We will partner with healthcare professionals to improve the diagnostic pathway for sarcomas, increasing speed and accuracy of diagnosis.
- We will work with the health services in all nations to ensure that all patients with suspected sarcoma are referred to a specialist centre at the appropriate stage in the diagnostic pathway.

Delays in the diagnostic pathway also occur after patients have been referred for further tests by their GP.

From our research so far, we have found there are a number of issues contributing to this. This includes the inaccurate reading of a scan or test; patients having multiple referrals to the wrong specialism; and patients not being referred to a specialist centre for further tests and to evaluate the correct care.

When healthcare professionals are not trained to accurately read scan results, patients can receive the wrong diagnosis. Equally, when pathologists are not specialised in looking at sarcoma biopsy samples, there is a higher chance of misdiagnosing the sarcoma as benign.⁶

GPs have told us that the referral system is not adequately set up for sarcomas, which often have vague symptoms. When it is not clear which area needs further testing (such as pains in the abdomen), a patient must be referred for each area, and then return if no problems are found. This leads to multiple referrals, increasing the time a patient must wait whilst bringing them no closer to diagnosis or treatment.

When sarcoma patients are not referred to a specialist sarcoma centre, where an expert team manages their care, there are poorer outcomes for patients.

In fact, being treated by a non-specialised team increases risk of local recurrence, and smaller margins, meaning that the sarcoma is more likely to come back.⁷ This can be down to poorly planned biopsies or surgeries by non-sarcoma specialists.⁸

Together, these factors delay a patient getting an accurate diagnosis and makes them less likely to receive the best possible treatment.⁹

“It is essential that our diagnostic pathways are clear. Primary care professionals need to be able to refer patients for a scan, where a trained sonographer or radiologist is able to determine whether there is a suspicion of sarcoma. These patients can then be referred directly to a specialist centre.”

**Anant Desai, Sarcoma Consultant Surgeon,
University Hospitals Birmingham NHS
Foundation Trust**

13%

of sarcoma patients said they were not treated by a specialist sarcoma team, a 3% increase from 2015.



⁶ Gerrand, C. Clinical guidelines for bone and soft tissue tumours. (2017).

⁷ Davis, A. M. et al. The impact of residual disease on local recurrence in patients treated by initial unplanned resection for soft tissue sarcoma of the extremity. *J. Surg. Oncol.* 66, 81–87 (1997).

⁸ Loong, H. H., Blay, J.-Y. & Munhoz, R. R. International Collaborations and Regional Challenges in Providing Specialist Multidisciplinary Sarcoma Care. *Am. Soc. Clin. Oncol. Educ. Book* 616–623 (2019) doi:10.1200/EDBK_239131.

⁹ Gerrand, C. Clinical guidelines for bone and soft tissue tumours. (2017).

Together, we can improve diagnosis and save lives

This report marks the beginning of a renewed emphasis on early diagnosis for Sarcoma UK. In the coming months, we will continue to work with clinicians and patients to develop an informed set of recommendations which contain detailed asks of policy makers.

We will use this report as a stimulus to begin discussions with policy makers, drawing their attention to the unfair delays which sarcoma patients face and routes by which to improve these.

In autumn 2020, we will publish these recommendations and call on policy makers to take action.

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More information around Sarcoma UK's policy and campaigning work at sarcoma.org.uk/policy

You can also contact policy@sarcoma.org.uk



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sarcoma.org.uk/policy

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